

# Electronic health records, platforms, libraries, and evidence: report on the Association of Academic Health Sciences Libraries symposium's keynote presentation by Kenneth Mandl\*

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## INTRODUCTION

The keynote speaker for the Association of Academic Health Sciences Libraries symposium on electronic health records (EHRs) and knowledge-based information was Kenneth Mandl. Mandl is associate professor at Harvard Medical School and director of the Intelligent Health Laboratory at the Children's Hospital Informatics Program, Harvard University–Massachusetts Institute of Technology Division of Health Sciences Technology. He is a pioneer in both consumer informatics and population health monitoring, and he has innovated and published extensively in the areas of personally controlled health records (PCHRs), disease outbreak detection, public health surveillance, and national health information infrastructure.

Mandl has reviewed and approved the following account of his keynote address, "Electronic Health Records: Platforms, Libraries, and Evidence."

## THE PROBLEM

Mandl began by stating several important questions that would be central to his presentation: "How do we get knowledge to the point of care? Where can we insert the knowledge necessary to drive better clinical care and ultimately contribute to health care reform?" He asserted that despite large investments in technology in our institutions, real processes are not well supported by the application of actual information or content. He described what he understood to be types of knowledge resources or evidence that might be considered in answering these questions. These types of evidence are:

- delivery of "evidence" for clinical decision making, such as traditional evidence in the journal literature, and clinical guidelines, of which one interesting example is Map of Medicine [1]

- "knowledge resources," which he divided into "consumer facing," the chief example being MedlinePlus, and "physician facing," as represented by such resources as UpToDate

- "next generation" knowledge resources, which are essentially data that contextualize medical decisions, such as a system being developed at Harvard Children's Hospital Informatics Program called AE-GIS that provides real-time disease surveillance [2]

- evidence about health information technology (HIT) for health information decision makers, such as information and knowledge that will be needed by the Regional Extension Centers that will help providers implement HIT; an example for this kind of knowledge is ItdotHealth: National Health IT Forum [3]

According to Mandl, libraries are already good at handling knowledge of the first type, that is, the primary literature, meta-analysis, evidence from clinical trials, and guidelines. Libraries also provide access to knowledge resources. In both these cases, the challenge may be in trying to place these types of knowledge into the clinical workflow. Next generation knowledge can come from many sources and be combined and presented in new ways. For instance, EHRs themselves could provide depositories of real information derived from patient records, which could support clinical decisions. An important potential role for libraries might be to curate and provide access to these data in new ways that support the clinical enterprise. Mandl did not point explicitly to a role for libraries in providing evidence about HIT for decision makers, but collaboration to provide this kind of knowledge seems to be another potential area for library involvement.

Having painted the landscape of "knowledge" in these terms, Mandl stated the essential problem as: "The library wants to deliver one of these forms of evidence *into* the clinician workflow. Is this possible?" His answer is that we *cannot* really do this very well. He goes on to explain why not. The explanation is complex, but it has a great deal to do with that the very nature of EHR systems is deeply flawed.

Health care reform includes a \$48 billion investment in HIT. EHR is a piece of that technology that is intended to move the country toward the "holy grail" of data and information exchange, liquidity, and accumulation so that knowledge can be brought to bear on clinical decision making at the point of care to improve health. But what are EHRs in fact? They provide documentation and billing. The sales pitch to a primary practice is that with an EHR or electronic medical record (EMR), the provider will be able to bill more. It will make the writing necessary to document billing easier by doing some of it for the physician. However, their use of EHRs, at least initially, will also slow down the process and reduce productivity.

Current EHRs do some things well and some less well. While they handle laboratory information reasonably well, medication management is not handled well because all the information about medications a patient may be taking is hard to collect and access in a single system. Comprehensive

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information may not be in the record, though the potential for improvement is there. Current systems do not promote communication, at least not outside the siloed systems of single organizations as they exist now. EHR systems are very expensive, and the per-physician costs are actually higher for smaller practices or health care organizations than they are for very large hospitals. Because of these high costs, the federal investment of \$48 billion may not, in fact will not, be enough to accomplish the end of spreading HIT and EHRs across the country.

Studies conducted by David Blumenthal, director of the Office of the National Coordinator for Health Information Technology, or ONC as it is now called, and others show that the adoption or implementation of anything like a comprehensive EHR is much lower than might have been thought. A study from 2008 shows that only about 4% of primary care practices have full EHRs [4]. Another study of hospitals from 2009 indicates that only about 1.5% of hospitals have implemented comprehensive EHRs [5]. It had been thought that the rate of adoption of EHRs would be much higher, on the order of 11% or more.

What are the reasons for these low rates of adoption? Are doctors luddites, or has the technology failed? This technology is needed, but it is not being implemented. Why not? One reason is that EHRs are very expensive. The cost is not just in purchasing the systems, but in the "pain and suffering" involved in implementing an electronic record: productivity suffers and the physician is slowed down, at least initially. The physician will see fewer patients, and volume of patients is extremely important because it translates into income. One estimate is that paying physicians \$40,000 each to implement EHRs would not be enough to offset the down side. Based on these factors, Mandl suggested two possible conclusions. One is that much more must be done to push the technology into practice. This conclusion translates into more money that will be needed to encourage adoption. The other conclusion, which Mandl favored, is that the technology has failed. It is not good technology or doctors would have adopted it and there would be less resistance and greater use.

The promise of EHRs has not been fulfilled, according to Mandl. He cited the fact that even with computerized physician order entry systems, the most widely adopted piece of the electronic system, medication ordering errors are frequent. In fact, new kinds of errors are even being made that are only possible in a poorly designed electronic environment [6].

To bring his argument to a point, Mandl summarized the shortcomings of EHRs. They:

- are very expensive
- are monolithic by design: big systems that do not integrate easily with other systems
- are tough to integrate into workflows
- reduce productivity
- are difficult to customize or to integrate across systems
- do not support information exchange

- do not support communication among physicians across or outside of same systems
- may be problematic due to agreements with EHR vendors with regard to provisions such as "hold harmless" clauses or "gag orders"

Once again, the bottom line is that even if it were possible to integrate knowledge-based information into EHR systems, the systems themselves are flawed.

## DISRUPTIVE INNOVATION

Mandl described disruptive innovation using the example of the Japanese car industry's effect on US automotive companies. Starting with a small, cheap car, Toyota, for instance, ended up turning the auto industry upside down. Could this type of disruption happen to the EHR market? That market is currently dominated by big, monolithic, complex systems, with a huge investment for health care organizations in the products. He concluded, however, that this kind of disruption could happen in HIT. One way is through building an EHR as an "iPhone-like" platform, which uses a common application programming interface that enables software developers to build "substitutable" applications for EHRs. This could push innovation to the edges, nimbly evolve functionality, avoid vendor lock, and shrink switching costs. This model was described in an article by Mandl and Kohane, "No Small Change for the Health Information Economy" [7]. It envisions applications being written by a widely distributed network of developers on a common platform that would allow users to cheaply and easily substitute better system components as they become available. That platform could be either open or proprietary. This could be done in either a provider-centered or patient-centered way, but the "substitutable model" is essential to this idea.

According to Mandl, there may be an emerging consensus around alternatives to the mainstream, vendor-centered EHRs and toward the creation of a "health Internet" that would include substitutable applications and would be characterized by distributed innovation, consumer engagement, and PCHRs as first-order members of the network. The administration's chief technology officer and others outside of the ONC are interested in this kind of development. Mandl suggested that there may be better opportunities for medical librarians to work from the consumer side to engage and serve patients, rather than work mainly through the clinical establishment as they seem often to have done and are trying to do now by seeking to integrate with EHRs.

## PERSONALLY CONTROLLED HEALTH RECORDS

Social networking sites for people with diseases are very heavily used and, while not equivalent to consulting with a physician, provide a comparatively inexpensive way for patients to access relevant health information. According to Mandl, the quality of the

information accessed is highly variable, but it is not bad and could be improved fairly readily. The question is, "Can the health care system actually help people in these online environments in ways that increase the quality of the information they are getting without disturbing this new and interesting milieu?"

Mandl observed that hospitals do not have a history of sharing information with each other or, in fact, with their patients. Hospitals view patient information as proprietary, they fear competition, and they are very concerned with privacy and security of information, a position that has been reinforced by the Health Insurance Portability and Accountability Act (HIPAA). Further, hospitals have no resources dedicated to information sharing. While patients have a right to their own records, they are usually provided only in hard copy at significant cost to the patient. In the 1990s, it was proposed that the patient record be provided electronically and that patients should have the means to request this information and to store, aggregate, and access these records. This would require some platform to support personal health records that would be analogous to the applications that can be used for personal financial management, such as Mint.com [8].

One such system to support patient-controlled records is Indivo [9]. Patients can request their records from all providers and download them to the Indivo server, creating a useful comprehensive personal health record. The collection of records in this system creates a potentially useful population health database. This PCHR stores all of an individual's medical history in a container with patient control and interoperability and under open standards. This allows patients to access their records and grant access to others in ways that are specific to the roles of those being granted access and that controls the portions of the record that they can access. Patients can store their records in a location of their choice and can annotate the record [10]. Indivo is open source, was developed with support from the Centers for Disease Control and Prevention and National Institutes of Health, and is built to public standards. It has been deployed in a number of clinical settings and companies, the latter deployment under the auspices of a consortium known as Dossia [11].

Individuals using this PCHR can subscribe using personal credentials; download their records; define who the record may be shared with, including their health care providers; and can export their record to another system if they wish. This PCHR model has been seen as the potential "disruptive solution for health care" [12]. The "ecosystem" that might surround the PCHR platform was described in an article in the *New England Journal of Medicine* in 2008 [13]. The Indivo source code has been used as the basis of Microsoft's HealthVault [14] and Google Health [15].

Mandl went on to describe how added value might be derived from PCHRs by applying a surveillance model to the population health databases that these aggregated records could create. Rich data could be

derived from these resources. Most users of PCHRs are willing to share aggregated and de-identified information from their records for population and public health purposes [16]. PCHR vendors and users would thus be able to create large accessible populations for public health study and intervention [17]. One company, Trialx.com [18], is already matching patients to clinical trials by using their personal health records from HealthVault or Google Health. Efforts of this kind could truly advance the clinical and translational research model. One important issue related to these proprietary or provider PCHRs is that they are not HIPAA-covered entities. They are only covered by "terms of use," which are entirely controlled by and in service to the provider, and they do not constitute true consent as it exists in most covered medical environments. This issue should be addressed through legislation or regulation.

Adoption of PCHRs has been slow to this point, but these systems are relatively new. Established EHR vendors still hold onto their data and have not opened up to export to PCHRs as yet. However, the requirements for "meaningful use" may force the issue of data exchange. Consumers do not yet perceive the value of the PCHR, because there are few health applications that can add value to the data. Regulatory issues need to be addressed such as the Clinical Laboratory Improvement Amendments, which may currently prevent laboratory results from being shared directly with patients. Consent issues are complex; terms of use are not true consent.

The next challenges with PCHRs include confronting the myth of personal control of care and of the individual's health information. Often this control is, in fact, family control, particularly for young patients or elderly parents. Another issue is what information flows across the application programming interface and who ultimately controls and owns the information that has been transferred? Can the PCHR be made as interesting and valuable to patients and consumers as, for instance, social networking around health issues already is?

## CONCLUSION

Mandl ended by talking about the difficulties that might be faced in the current environment with integrating knowledge-based resources into the clinical workflow. He had already stated that this could not be done very well, in part because these systems face inherent limitations, as outlined above. Further, absent the substitutable applications model, the problem would have to be solved repeatedly with different vendors of EHR systems. Also one would have to deal with all sorts of local variations from one institution to the next because no two implementations are exactly alike, even for a particular EHR vendor. The platform model that allows for substitutable applications actually provides a better architecture to insert knowledge in the right places in ways that are highly scalable.



Currently, the best opening for libraries to provide information resources to patients may be in the area of PCHRs or, even more immediately, in provision of consumer health information. However, there is still the potential to take advantage of the government's levers of reimbursement and meaningful use to achieve something like the platform model of an EHR. Meaningful use as defined by the Health Information Technology for Economic and Clinical Health Act will include the requirement to export patient information from EHRs to personal health record systems and will require health information exchange based on standards. It could include provisions that enable a "library app" to be run within the certified EHR. If librarians were able to successfully push for this now, the integration of knowledge-based resources into EHRs could become a tractable task.

Other opportunities for libraries that Mandl mentioned during his talk were delivering evidence to support clinical decision making and providing knowledge resources, both physician facing and consumer facing. Both of these are being done now, though not usually as integrated resources in clinical systems or in the clinical workflow. As Mandl observed, there are substantial challenges to accomplishing real integration. Other opportunities Mandl pointed to were collecting, curating, and providing access to data derived from EHR systems. These could be done in the context of next generation knowledge management systems to support and contextualize clinical decision making.

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